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*Linda Lelling* PI - Signature *8/28/96* Date

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## **Introduction:**

It has been widely recognized that the greatest potential for reducing breast cancer mortality may be realized through aggressive implementation of breast cancer prevention (BCP), hence, the initiation and implementation of three national breast cancer prevention clinical trials: the Women's Health Trial, NSABP Breast Cancer Prevention Trial (BCPT), and the Women's Health Initiative (1,2,3). National data indicate, however, that minority and low-income women are often underrepresented in such clinical trials (2,3). In fact, current accrual to the NSABP BCPT includes only 5% minority representation among its over 8,000 subjects (2). Unless factors influencing this limited participation can be identified and alternate strategies defined, generalizability of study results to economically disadvantaged minority women will be limited. This problem is particularly significant for African-American women given the disproportionate mortality and morbidity due to breast cancer compared to Caucasian women (4).

Decisions to participate in breast cancer prevention (BCP) research trials and perform BCP behavior occur within the context of beliefs, perceptions, social roles, economic realities and may vary within culture. Reasons for the difficult recruitment of African-American women for participation in national BCP trials has been assumed to be related to: 1) hesitancy to participate in research (ethical issues relating to efficacy, randomization, confidentiality, side effects, inconvenience and cost); 2) health professional's lack of information regarding research trials; 3) women's lack of knowledge regarding cancer prevention and opportunities for participation in research; 4) unwillingness to consider investigational trials as opportunities for participation by healthy individuals; and 5) historical barriers regarding research participation (5). There has been little verification of the impact of these assumed barriers.

## **Purpose:**

The purpose of this study is to identify and explore cognitive, social and environmental factors influencing African American women's willingness to participate in BCP research and intention to practice BCP behavior. The objectives are to: 1) identify culturally salient beliefs and attitudes related to BCP behavior practice and research participation using a focus group technique; 2) develop a valid and reliable theoretically based instrument; and 3) identify the relative strength and interaction of factors influencing willingness to participate in BCP research and intention to practice BCP behavior via a descriptive survey.

## **Theoretical Framework:**

The theoretical basis identifying variables to be considered in this study is derived from the health Belief Model (HBM), Theory of Reasoned Action (TRA), Social Learning Theory (SLT) and related literature organized according to the PRECEDE Health Education Planning Framework (6). These theoretical models suggest variables that have related significantly to breast cancer detection behavior in past research. Based on preliminary findings, similar

factors would have applicability for explaining willingness to participate in BCP research and perform BCP behavior.

### **Research Design and Methods:**

A combined qualitative and quantitative approach will be used in the research. A population of African-American women attending outpatient clinics at a large Los Angeles county hospital will be the target population for this study. Salient beliefs will be determined via 6-8 focus group sessions (N=5-10/group). An instrument will then be developed based on the major themes identified from these discussions related to consequential beliefs, social norms, and factors facilitating/inhibiting willingness to participate in BCP research and intention to practice BCP behavior. Feasibility and psychometric properties of the instrument will be determined via a pilot study (N=40) prior to the descriptive survey (N=200). Focus group data will be analyzed using manifest content analysis. Reliability and validity will be determined by the Content Validity Index, internal consistency and test-retest procedures. Descriptive survey data will be analyzed using univariate, bivariate and multivariate techniques. Findings from this study will be useful for developing culturally sensitive communication messages and intervention strategies tailored to the needs of low-income, African-American women and aimed at enhancing BCP research participation and practice.

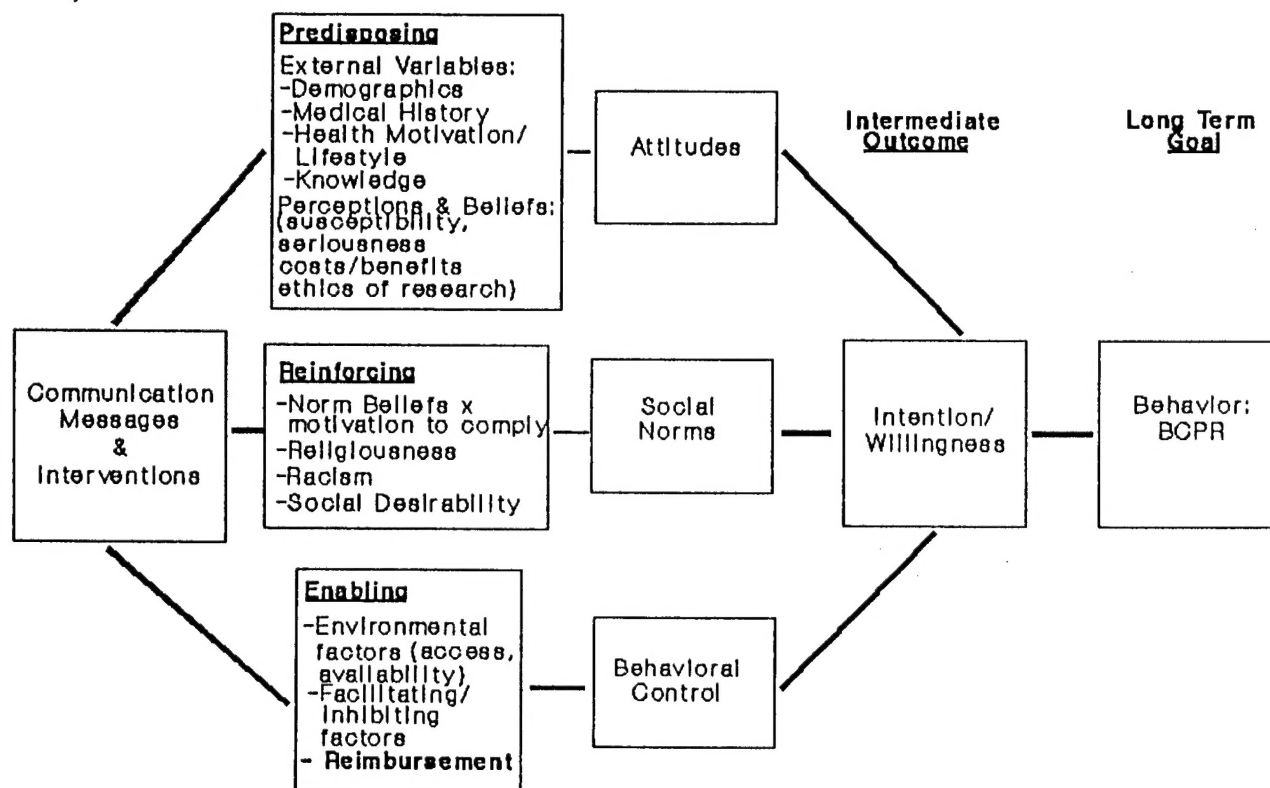
### **Body:**

As identified in the scope of work the tasks to be completed in the second year of funding focused on developing, pre-testing and pilot testing the newly developed survey questionnaire identifying factors influencing African American women's decisions to participate in breast cancer prevention research.

### **Questionnaire Development**

Based on focus group findings with validation by focus group participants, categories of themes of factors potentially impacting breast cancer research participation among African American women were identified. These included: demographic characteristics (age, education, income, insurance status, health history, family history of breast cancer, and marital status); beliefs about medical research (positive and negative); benefits of medical research; barriers to participation; facilitating factors; racism or discrimination in health care delivery; religiousness; social influences; and knowledge. The theoretical framework guiding this research also included examining the impact of Health Belief Model variables (perceived susceptibility, perceived seriousness, health motivation), and Theory of Reasoned Action variables (general attitudes, perceived behavioral control, and social norms). Figure 1.

**Figure 1. Variables Potentially Impacting Breast Cancer Prevention Research Participation**



**BCPR - Breast Cancer Prevention Research Participation**

A questionnaire was developed guided by focus group findings and constructs from the theoretical model. Pretesting of the questionnaire was conducted among the focus group participants. A total of 20 focus group participants reviewed the questionnaire for face validity. Redundant items were deleted, and confusing statements were clarified.

Subsequently the questionnaire was reviewed by a judge panel of experts: PhD Psychologist; RN, PhD Director of Nursing Research at Harbor UCLA Medical Center; MD, PhD Cancer Expert; and RN, PhD Anthropologist who has experience working with the African American population. The content validity for the newly developed questionnaire ranged from .58 to 1.00 for the individual scales.

<b>Scale</b>	<b>Number of Items</b>	<b>CVI</b>
Demographics	7	.96
Positive Beliefs	9	1.00
Negative Beliefs	15	1.00
Facilitating Factors	20	1.00
Benefits	10	1.00
Barriers	13	1.00
Intention	2	1.00
Reference	7	1.00
Social Norms	1	1.00
Attitudes	4	.58
Behavioral Control	3	1.00
Knowledge	10	1.00
Health Behavior	2	1.00
Health History	2	1.00

As a result of focus group participant's review, the format of the questionnaire was also revised to ease completion. Although the questionnaire was lengthy, focus group participants suggested that an explanation be included in the introductory letter explaining that the questionnaire was long but that all information was very important and would be useful.

A pilot test was subsequently conducted recruiting African American women from the Cardiology and Breast Clinics at Harbor-UCLA Medical Center. Forty-five African American women completed the questionnaire while waiting in clinic for their appointment and were asked to complete and return the second questionnaire within one week using a postage paid enclosed envelope. Demographic characteristics are described in Table 1.

**Table 1. Respondent Characteristics (N=45): Focus Group=20; Pilot=25**

Age	
Mean years	51.27
Range	35 - 89
Education	
Mean years	12.68
Range	4 - 20
< HS	24 %
≥ HS	76 %



Marital Status		
	Single	29.0%
	Married	17.7%
	Sep/Divorced	35.6%
	Widowed	17.8%
Yearly Household Income		
	≤ \$10,999	25.6%
	\$11,000-\$20,999	18.6%
	\$21,000-\$39,999	11.7%
	\$40,000-\$50,000	7.0%
	> \$50,000	2.3%
Employment		
	Full Time	11.1%
	Part Time	15.6%
	Retired	11.0%
	Disabled	42.2%
	Not Employed	20.0%
Health Insurance		
	Medicare	9.1%
	Medical	29.5%
	Private	25.0%
	None	22.7%
	Other	13.6%

Only seven participants returned the second questionnaire which was not sufficient to complete the test-retest reliability. Internal consistency reliability was determined for all scales of the instrument using Cronbach's Alpha for continuous variables and Kuder Richardson's 20 (KR-20) for dichotomous variables (Table 2).

**Table 2. Reliability**

<u>Scale</u>	<u>No. Items</u>	<u>Cronbach Alpha</u>
<u>Health Belief Model Constructs</u>		
Seriousness	7	.71
Susceptibility	5	.83
Health Motivation	7	.72

### Newly Developed Scales

Positive Beliefs	9	.70
Negative Beliefs	15	.86
Facilitating Factors	20	.86
Benefits	10	.85
Barriers	13	.80
Intention	2	.80
Referents <sup>a</sup>	7	.64
Attitude	4	.50
Behavioral Control <sup>a</sup>	3	.50
Knowledge	10	.62*

### Additional Instruments

Racism	9	.81
Religiousness	4	.85
Social Desirability	5	.35

\* Kuder-Richardson's estimate of reliability for dichotomous variables.

<sup>a</sup> Reliability was improved by dropping one item.

Based on the content validity index and reliability determination, the questionnaire was adjusted to delete items for the Behavioral Control and Referent scales to improve the reliability. The final version of the questionnaire was again reviewed by the judge panel for content validity which was determined to be .98 for the entire questionnaire.

A mailing list requesting the names of 10,000 African American women ages 50-79 was purchased from Mailing Lists of Southern California. The questionnaires were printed and the mail survey has been sent out in conjunction with recruitment efforts for the Women's Health Initiative Program. During the final year of the fellowship data from the survey will be analyzed to determine factors influencing African American women's decisions to participate in breast cancer prevention research, particularly as it relates to the Women's Health Initiative Program. The questionnaire is included in Appendix A.

### **Outcomes of Research to Date**

An abstract and subsequent manuscript was written related to findings from the focus groups entitled "African American Women's Perspectives on Research Participation" (Appendix B). This work was nominated for the Oncology Nursing Society/Schering Excellence in Cancer Nursing Award and was presented at the Advanced Nursing Research Session of the Oncology Nursing Society Annual Congress in Philadelphia, May 1996. A poster presentation of the focus group findings was also presented at the Conference on "Minority Recruitment to Clinical Trials" in Washington, DC, January 1996. In addition to the research presentations an instructional session entitled "Insider/Outsider Perspectives" in the Conduct of Research in

Special Populations was presented at the Oncology Nursing Society Annual Congress in May 1996. In addition, I was invited to speak at the National Nutritionists Training Session for the Women's Intervention Nutrition Study, a multi-site clinical trial evaluating the impact of a low-fat diet on breast cancer recurrence, addressing the topic of recruitment, particularly among special populations. I have also recently been invited to participate in a writing group as part of the Women's Health Initiative addressing the issue of the impact of insurance status on research participation.

The efforts of this current research along with prior work regarding Cancer Prevention and Control among minority populations was also recognized by receipt of the Outstanding Nursing Achievement Award for 1996 at the Harbor-UCLA Medical Center. Finally, during the past year, I was appointed as Chair of the Research Committee for the Oncology Nursing Society having been a member of this committee and study section reviewing small grants, fellowships and targeted initiatives for funding for the last 4 years. This fellowship support has been very instrumental in furthering the development of my research career in the area of breast cancer research particularly in the area of minority populations.

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### **Women's Thoughts About Breast Cancer**

Thank you for agreeing to answer these questions about breast cancer. We are interested in learning how women like yourself feel about breast cancer and Medical Research. Although this is a long questionnaire, your responses are appreciated and will be very useful for developing programs to help Black women learn more about breast cancer and ongoing research.

There are no right or wrong answers, only your important thoughts and opinions. We are interested most in what you really think and what you really do not what you think you "should do". Please answer **EVERY** question as best you can. Your name is not identified on this questionnaire. All responses are totally confidential (secret). An addressed, postage paid envelope is enclosed for return of the questionnaire.

If you need any help in completing the questionnaire or have any questions, we would be happy to assist you over the phone. You may call Linda or Barbara at (310) 222-2217 or (310) 222-2219. Again, every woman's thoughts and opinions are important to us. We appreciate your time and effort in completing the questionnaire. This is an opportunity for you to help fight the battle against breast cancer for yourself, your daughters and generations of women to come.

For Office Use Only

Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_  
IDC: \_\_\_\_\_

**Part I**

These questions ask for some information that will help us to know more about the women who answer the survey. **PLEASE CIRCLE THE NUMBER THAT BEST DESCRIBES YOUR ANSWER OR FILL IN THE BLANKS.**

1. What is your birthdate?

\_\_\_\_ / \_\_\_\_ / \_\_\_\_  
mo day yr

2. What is your zip code?

\_\_\_\_ / \_\_\_\_ / \_\_\_\_ / \_\_\_\_ / \_\_\_\_

3. What is your racial/ethnic background?

1 - Black

2 - African American

3 - White

4 - Hispanic/Latino

5 - Asian - Pacific Islander

6 - Other \_\_\_\_\_  
(Specify)

4. How many years of school have you finished? **(Please circle highest grade completed)**

Elementary 1 2 3 4 5 6 7 8

High School 9 10 11 12

College 13 14 15 16

Graduate School 17 18 19 20

5. What is your marital status?

1. Single, never married

4. Separated/Divorced

2. Living together as married

5. Widowed

3. Married

6. What is your yearly household income?

1. Less than \$5,000

4. \$21,000 - 30,999

7. More than \$50,000

2. \$5,000 - \$10,999

5. \$31,000 - \$39,999

3. \$11,000 - \$20,999

6. \$40,000 - \$50,000

**PLEASE GO TO NEXT PAGE**

7. What type of health insurance do you have?

- |                      |                                 |
|----------------------|---------------------------------|
| 1. MEDICARE          | 5. MEDICARE & MEDI-CAL          |
| 2. HMO               | 6. No Insurance                 |
| 3. MEDI-CAL          | 7. MEDICARE & Private Insurance |
| 4. Private Insurance | 8. Other _____<br>(Specify)     |

8. Where do you usually receive medical care?

1. Private doctor
2. County clinic
3. Emergency Room
4. HMO
5. Other \_\_\_\_\_  
(Specify)

9. Where do you usually get information about health? **(CIRCLE ALL THAT APPLY)**

- |  |                             |
|--|-----------------------------|
| 1. Doctor/Doctor's Office                | 4. Television               |
| 2. Newspaper/Magazine                    | 5. Radio                    |
| 3. Word of mouth (friends, family, etc.) | 6. Other _____<br>(Specify) |

10. Have you ever been told you have any of the following health problems?

- |                              |         |                               |
|------------------------------|---------|-------------------------------|
| 1. Heart disease             | No ____ | Yes ____                      |
| 2. Diabetes (Sugar in blood) | No ____ | Yes ____                      |
| 3. High blood pressure       | No ____ | Yes ____                      |
| 4. Cancer                    | No ____ | Yes ____ (If yes, type _____) |

11. Has anyone in your family ever had breast cancer?

No \_\_\_\_

Yes \_\_\_\_ If yes, specify:

- |           |                |                |
|-----------|----------------|----------------|
| 1. Mother | 3. Grandmother | 5. Daughter    |
| 2. Sister | 4. Aunt        | 6. Other _____ |

**PLEASE GO TO NEXT PAGE**

## Part II

This set of questions asks your thoughts and opinions about health behavior and breast cancer. **PLEASE CIRCLE ONE NUMBER ON EACH LINE.**

		<u>Disagree</u>	<u>Somewhat Disagree</u>	<u>Not Applicable/ Not Sure</u>	<u>Somewhat Agree</u>	<u>Agree</u>
12.	I want to discover health problems early.	1	2	3	4	5
13.	Maintaining good health is extremely important to me.	1	2	3	4	5
14.	I search for new information to improve my health.	1	2	3	4	5
15.	I feel it is important to carry out activities that will improve my health.	1	2	3	4	5
16.	I eat well balanced meals.	1	2	3	4	5
17.	I exercise at least 3 times a week.	1	2	3	4	5
18.	I have regular health check-ups even when I am not sick.	1	2	3	4	5
19.	I do breast self-exam at least once every month.	1	2	3	4	5
20.	I have had at least one mammogram in my lifetime.	1	2	3	4	5
21.	Is it extremely likely that I will get breast cancer in the future.	1	2	3	4	5
22.	I feel I will get breast cancer in the future.	1	2	3	4	5
23.	There is a good possibility I will get breast cancer in the next 10 years.	1	2	3	4	5
24.	My chances of getting breast cancer are great.	1	2	3	4	5
25.	I am more likely than the average woman to get breast cancer.	1	2	3	4	5
26.	I have no control over whether I will get breast cancer.	1	2	3	4	5

**PLEASE GO TO NEXT PAGE**

		<u>Disagree</u>	<u>Somewhat Disagree</u>	<u>Not Applicable/ Not Sure</u>	<u>Somewhat Agree</u>	<u>Agree</u>
27.	The thought of breast cancer scares me.	1	2	3	4	5
28.	When I think about breast cancer, my heart beats faster.	1	2	3	4	5
29.	I am afraid to think about breast cancer.	1	2	3	4	5
30.	Problems I would experience with breast cancer would last a long time.	1	2	3	4	5
31.	Breast cancer would threaten a relationship with my boyfriend, husband or partner.	1	2	3	4	5
32.	If I had breast cancer, my whole life would change.	1	2	3	4	5
33.	If I developed breast cancer, I would not live longer than 5 years.	1	2	3	4	5

### **Part III**

Listed below are a few statements about your relationships with others. **HOW MUCH IS EACH STATEMENT TRUE OR FALSE FOR YOU? (CIRCLE ONE NUMBER ON EACH LINE).**

		<u>Totally True</u>	<u>Mostly True</u>	<u>Don't Know</u>	<u>Mostly False</u>	<u>Totally False</u>
34.	I am always courteous even to people who are disagreeable.	1	2	3	4	5
35.	There have been times when I took advantage of someone.	1	2	3	4	5
36.	I sometimes try to get even rather than forgive and forget.	1	2	3	4	5
37.	I sometimes feel resentful when I don't get my way.	1	2	3	4	5
38.	No matter who I'm talking to, I'm always a good listener.	1	2	3	4	5

**PLEASE GO TO NEXT PAGE**



#### **Part IV**

Some women have different thoughts about breast cancer risk. **PLEASE READ EACH STATEMENT BELOW AND TELL US IF YOU AGREE, DISAGREE OR ARE NOT SURE HOW YOU FEEL ABOUT EACH STATEMENT.**

39. Which of the following are risk factors or conditions that may increase a women's chance of developing breast cancer?
- |                                    |          |             |             |
|------------------------------------|----------|-------------|-------------|
| a) Age over 50 years               | 1. Agree | 2. Not Sure | 3. Disagree |
| b) Large breasts                   | 1. Agree | 2. Not Sure | 3. Disagree |
| c) Family history of breast cancer | 1. Agree | 2. Not Sure | 3. Disagree |
| d) Injury to breast                | 1. Agree | 2. Not Sure | 3. Disagree |
| e) Obesity (overweight)            | 1. Agree | 2. Not Sure | 3. Disagree |
40. Breast cancer is the most common cancer affecting women in the United States.
1. Agree                      2. Not Sure                      3. Disagree
41. Few breast cancers are found by women themselves.
1. Agree                      2. Not Sure                      3. Disagree
42. Breast cancer found at an early stage can be cured.
1. Agree                      2. Not Sure                      3. Disagree
43. Which of the following exams are used to find breast cancer? **(PLEASE CIRCLE ALL THAT APPLY).**
- |                     |   |
|---------------------|---|
| 1. Chest X-ray      | 4. Bone Scan                                |
| 2. Mammogram        | 5. Breast Exam Performed by Doctor or Nurse |
| 3. Breast Self-Exam |   |
44. Signs and symptoms of breast cancer include; **(PLEASE CIRCLE ALL THAT APPLY).**
1. Painful Breast Lump
  2. Painless Breast Lump
  3. Chest Pain
  4. Nipple Discharge

**PLEASE GO TO NEXT PAGE**

**PART V**

45. The following questions ask your thoughts and opinions about Medical Research. **PLEASE CIRCLE ONE NUMBER ON EACH LINE:**

		<b><u>Disagree</u></b>	<b><u>Somewhat Disagree</u></b>	<b><u>Not Sure</u></b>	<b><u>Somewhat Agree</u></b>	<b><u>Agree</u></b>
a)	Taking part in research would make me feel better physically.	1	2	3	4	5
b)	Taking part in research would be important for my health.	1	2	3	4	5
c)	Benefits of being in a research study outweigh any difficulties such as taking pills, making changes in diet and keeping clinical appointments.	1	2	3	4	5
d)	Medical Research sponsored by the Government is safe.	1	2	3	4	5
e)	Taking part in a research study is important because it could help others even if it does not help me.	1	2	3	4	5
f)	I trust doctors and nurses doing the research have my best interest at heart.	1	2	3	4	5
g)	Research is important in order to find better ways to prevent and treat breast cancer.	1	2	3	4	5
h)	People who take part in research are admired by others.	1	2	3	4	5
i)	Most people do not know about Medical Research.	1	2	3	4	5

**PLEASE GO TO NEXT PAGE**

46. Please rate how important each of the following **BENEFITS** of being in a research study would be to you **(CIRCLE ONE NUMBER ON EACH LINE):**

		<b><u>Not Important</u></b>	<b><u>Slightly Important</u></b>	<b><u>Not Sure</u></b>	<b><u>Very Important</u></b>	<b><u>Extremely Important</u></b>
a)	Careful medical followup.	1	2	3	4	5
b)	Possibility of lowering my chance of getting or dying from breast cancer.	1	2	3	4	5
c)	Possibility of preventing others from getting breast cancer.	1	2	3	4	5
d)	Increasing my knowledge about breast cancer.	1	2	3	4	5
e)	Increasing scientific knowledge.	1	2	3	4	5
f)	Feel good about myself because I would be part of a research effort.	1	2	3	4	5
g)	Less worry about breast cancer.	1	2	3	4	5
h)	Learning more about my own body.	1	2	3	4	5
i)	Free medical check-ups.	1	2	3	4	5
j)	Free mammograms	1	2	3	4	5

**PLEASE GO TO NEXT PAGE**

47. Participation in Medical Research **WOULD BE OF INTEREST** to me if **(CIRCLE ONE NUMBER ON EACH LINE):**

		<u>Disagree</u>	<u>Somewhat Disagree</u>	<u>Not Sure</u>	<u>Somewhat Agree</u>	<u>Agree</u>
a)	There was no cost to me.	1	2	3	4	5
b)	I received cash payment for my time.	1	2	3	4	5
c)	Free health check-ups were included in the program.	1	2	3	4	5
d)	I Received cash payment for transportation costs.	1	2	3	4	5
e)	I had a high risk of developing breast cancer.	1	2	3	4	5
f)	I received cash payment for child or elder care so that I could attend required visits.	1	2	3	4	5
g)	My doctor recommended that I participate.	1	2	3	4	5
h)	The programs were available during evening or weekend hours.	1	2	3	4	5
i)	I received information about the results of the research.	1	2	3	4	5
j)	I received cash payment to help me do what the program requires (e.g. follow a special diet)	1	2	3	4	5
k)	I felt the doctor was honest about what would be done in the research program.	1	2	3	4	5
l)	The research program involved diet or exercise.	1	2	3	4	5
m)	Research visits could be scheduled during my regular doctor or clinic visits.	1	2	3	4	5

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Participation in Medical Research **WOULD BE OF INTEREST** to me if:

		<u>Disagree</u>	<u>Somewhat Disagree</u>	<u>Not Sure</u>	<u>Somewhat Agree</u>	<u>Agree</u>
n)	I had a clear understanding of all the possible <u>risks</u> that might be involved in the research.	1	2	3	4	5
o)	I had a clear understanding of all the possible <u>side effects</u> that might occur.	1	2	3	4	5
p)	The program involved taking a medication by mouth only.	1	2	3	4	5
q)	Information about the program was presented by African American or Black health care personnel.	1	2	3	4	5
r)	I had a clear understanding of what would be expected of me during the research study.	1	2	3	4	5
s)	I had a clear understanding of all the possible <u>benefits</u> that might result from taking part in the research.	1	2	3	4	5
t)	The program was available in my local community.	1	2	3	4	5

**PLEASE GO TO NEXT PAGE**

48. Participation in Medical Research would **NOT** be of interest to me because: **(CIRCLE ONE NUMBER ON EACH LINE)**

	<u>Disagree</u>	<u>Somewhat Disagree</u>	<u>Not Sure</u>	<u>Somewhat Agree</u>	<u>Agree</u>
a) I would feel like I was a guinea pig.	1	2	3	4	5
b) I would not know if the research treatment would work.	1	2	3	4	5
c) I might get breast cancer by taking part in the research.	1	2	3	4	5
d) I don't trust researchers.	1	2	3	4	5
e) I don't want to be experimented on.	1	2	3	4	5
f) There might be side effects of the medication.	1	2	3	4	5
g) It might cause pain, (e.g., blood drawing).	1	2	3	4	5
h) I don't want to be given "fake" medication (placebo).	1	2	3	4	5
i) I would not be able to choose the treatment I want.	1	2	3	4	5
j) It might cause breast cancer.	1	2	3	4	5
k) Researchers don't always tell you what they are going to do.	1	2	3	4	5
l) I don't want to be the "first" to try new things.	1	2	3	4	5
m) I just don't understand research.	1	2	3	4	5
n) I don't want to think about breast cancer.	1	2	3	4	5
o) I think Medical Research is for people who have a disease not for healthy people.	1	2	3	4	5
p) I don't trust research sponsored by the government.	1	2	3	4	5

**PLEASE GO TO NEXT PAGE**

49. Participation in Medical Research would be **HARD** for me because **(CIRCLE ONE NUMBER ON EACH LINE):**

		<b><u>Disagree</u></b>	<b><u>Somewhat Disagree</u></b>	<b><u>Not Applicable/ Not Sure</u></b>	<b><u>Somewhat Agree</u></b>	<b><u>Agree</u></b>
a)	I don't have the time.	1	2	3	4	5
b)	It may require extra trips to the hospital or clinic.	1	2	3	4	5
c)	I don't have transportation.	1	2	3	4	5
d)	I have too many other responsibilities at home (caring for children, relatives).	1	2	3	4	5
e)	I don't like to take pills.	1	2	3	4	5
f)	I would have a hard time changing my diet.	1	2	3	4	5
g)	I would have a hard time remembering to take pills every day.	1	2	3	4	5
h)	My family does not want me to participate.	1	2	3	4	5
i)	My friends to not want me participate.	1	2	3	4	5
j)	I'm too old to participate.	1	2	3	4	5
k)	I'm too sick to participate.	1	2	3	4	5
l)	I'm too tired to participate.	1	2	3	4	5
m)	It would cost too much money.	1	2	3	4	5

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## Part VI

This set of questions asks your thoughts and opinions about participating in Medical Research. **PLEASE CIRCLE ONE NUMBER ON EACH LINE:**

50. If you were thinking about participating in a Medical Research program to prevent breast cancer, would you:

	<u>No</u>	<u>Probably Not</u>	<u>Not Sure</u>	<u>Probably Yes</u>	<u>Yes</u>
a. Discuss it with your <u>doctor/nurse</u> .	1	2	3	4	5
b. Think about it by <u>yourself</u> .	1	2	3	4	5
c. Discuss it with your <u>pastor</u> .	1	2	3	4	5
d. Discuss it with your <u>family</u> .	1	2	3	4	5
e. Discuss it with your <u>friends</u> .	1	2	3	4	5
f. Pray about it and ask <u>God's help</u> in making a decision.	1	2	3	4	5
g. Get more information about the subject.	1	2	3	4	5
h. Want to talk to other women already in the research program.	1	2	3	4	5
51. Do <u>most people</u> who are important to you think you should participate in Medical Research for breast cancer?	1	2	3	4	5
52. Do you <u>want</u> to participate in Medical Research for breast cancer?	1	2	3	4	5
53. Do you <u>plan</u> to participate in Medical Research for breast cancer?	1	2	3	4	5
54. How <u>easy or hard</u> would it be for you to participate in a Medical Research program?					

1.  
Very  
Hard

2.  
Mostly  
Hard

3.  
Not Sure

4.  
Mostly  
Easy

5.  
Very  
Easy

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55. How easy or hard would it be for you to participate in a Medical Research program that involved making changes in your diet?

- |      |        |          |        |      |
|------|--------|----------|--------|------|
| 1.   | 2.     | 3.       | 4.     | 5.   |
| Very | Mostly | Not Sure | Mostly | Very |
| Hard | Hard   |          | Easy   | Easy |

56. How easy or hard would it be for you to participate in a Medical Research program that involved taking a medication by mouth every day?

- |      |        |          |        |      |
|------|--------|----------|--------|------|
| 1.   | 2.     | 3.       | 4.     | 5.   |
| Very | Mostly | Not Sure | Mostly | Very |
| Hard | Hard   |          | Easy   | Easy |

57. Participating in Medical Research to prevent or better treat breast cancer would be:

- |             |             |          |           |           |
|-------------|-------------|----------|-----------|-----------|
| 1.          | 2.          | 3.       | 4.        | 5.        |
| Very        | Mostly      | Not Sure | Mostly    | Very      |
| Unimportant | Unimportant |          | Important | Important |

58. I think cures for cancer are known but are not being shared with the people?

- |          |          |          |          |       |
|----------|----------|----------|----------|-------|
| 1.       | 2.       | 3.       | 4.       | 5.    |
| Disagree | Somewhat | Not sure | Somewhat | Agree |
|          | Disagree |          | Agree    |       |

59. I think breast cancer research is ethical.

- |          |          |          |          |       |
|----------|----------|----------|----------|-------|
| 1.       | 2.       | 3.       | 4.       | 5.    |
| Disagree | Somewhat | Not sure | Somewhat | Agree |
|          | Disagree |          | Agree    |       |

60. I think breast cancer research is effective.

- |          |          |          |          |       |
|----------|----------|----------|----------|-------|
| 1.       | 2.       | 3.       | 4.       | 5.    |
| Disagree | Somewhat | Not sure | Somewhat | Agree |
|          | Disagree |          | Agree    |       |

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61. Which of the following statements best describes your participation in Medical Research right now?
1. **I AM NOT** thinking about participating in a research program to prevent breast cancer and am not interested at this time.
  2. **I AM** thinking about participating in a Medical Research program to prevent breast cancer and would like more information.
  3. I already know about available breast cancer prevention research programs and **I AM INTERESTED** in joining a program.
  4. I already know about available breast cancer prevention research programs and am **NOT INTERESTED** in joining a program.
  5. **I AM ALREADY PARTICIPATING** in a breast cancer prevention research program. (If so, which program):
    - a. Women's Health Initiative.
    - b. Breast Cancer Prevention Trial (Tamoxifen).
    - c. Other: \_\_\_\_\_
62. If you were thinking about participating in a breast cancer research program or are already participating, which program would/do you prefer? **(CIRCLE ALL THAT APPLY)**
1. A program that would change diet.
  2. A program that involves taking a pill by mouth.
  3. Completing questionnaires and forms only.
  4. Other \_\_\_\_\_  
(Specify)
63. Have you ever participated in any type of Medical Research program?
- NO \_\_\_\_\_ YES \_\_\_\_\_, If yes, type \_\_\_\_\_

**PLEASE GO TO NEXT PAGE**

**PART VII**

64. The following statements ask your thoughts and opinions about medical care you have received.  
**PLEASE CIRCLE ONE NUMBER ON EACH LINE:**

	<u>No</u>	<u>Probably Not</u>	<u>Not Sure</u>	<u>Probably Yes</u>	<u>Yes</u>
a) Doctors treat black women and white women the same.	1	2	3	4	5
b) Sometimes, if you are black in a white doctor's office, it is as if you do not belong there.	1	2	3	4	5
c) Racial discrimination in research is common.	1	2	3	4	5
d) In most hospitals, black women and white women get the same kind of care.	1	2	3	4	5
e) Doctors and nurses act the same way to white and black older women.	1	2	3	4	5
f) Blacks have the same opportunities as whites to participate in Medical Research.	1	2	3	4	5
g) If a black women and a white women were participating in the same research program they would be treated the same.	1	2	3	4	5
h) Black women can receive the care they want as equally as white women.	1	2	3	4	5
i) Black older women have fewer options to take part in research.	1	2	3	4	5

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### **Part VIII**

The following statements ask your thoughts and opinions about your religious beliefs. **PLEASE CIRCLE ONE NUMBER WHICH BEST DESCRIBES YOUR RESPONSE.**

65. How religious would you say you are?

- |                     |                        |                |                      |                    |
|---------------------|------------------------|----------------|----------------------|--------------------|
| 1.<br>Not<br>At All | 2.<br>Not<br>Very Much | 3.<br>Somewhat | 4.<br>Pretty<br>Much | 5.<br>Very<br>Much |
|---------------------|------------------------|----------------|----------------------|--------------------|

66. When you have decisions to make, in your everyday life, how often do you ask yourself what God would want you to do, or ask God for help in making the decision?

- |             |              |                 |             |                  |
|-------------|--------------|-----------------|-------------|------------------|
| 1.<br>Never | 2.<br>Seldom | 3.<br>Sometimes | 4.<br>Often | 5.<br>Very Often |
|-------------|--------------|-----------------|-------------|------------------|

67. On the average, how often have you attended religious worship services (i.e., Sunday morning, evening, and/or other days) during the last year?

- |             |                                |                                   |                                     |                                      |
|-------------|--------------------------------|-----------------------------------|-------------------------------------|--------------------------------------|
| 1.<br>Never | 2.<br>A Few<br>times<br>a Year | 3.<br>Once or<br>Twice a<br>Month | 4.<br>Weekly or<br>almost<br>Weekly | 5.<br>More<br>than<br>Once a<br>Week |
|-------------|--------------------------------|-----------------------------------|-------------------------------------|--------------------------------------|

68. To what extent are you conscious of some religious goal or purpose in life which serves to give direction to your life?

1. Not at all
2. To a small extent
3. To a moderate extent
4. To a large extent
5. To a very large extent

Thank you for your time. Your answers will be helpful for developing programs to help women prevent breast cancer.

**Comments:**

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AFRICAN AMERICAN WOMEN'S PERSPECTIVES  
ON RESEARCH PARTICIPATION

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## ABSTRACT

Nationally Funded Research trials aimed at breast cancer prevention in women at high risk are currently underway (Breast Cancer Prevention Trial, Women's Health Initiative). Recruitment of African American women for participation in these trials has been difficult. Without adequate representation, generalizability of findings to the African American population will be limited. Few studies have examined reasons for the lack of African American participation in clinical trials. The purpose of this study is to identify the attitudes and beliefs of African American women regarding breast cancer prevention research. The conceptual framework guiding the study is based on the Health Belief Model and Theory of Reasoned Action. Focus groups were used to explore beliefs and attitudes about breast health, breast cancer, breast cancer prevention, medical research, and ways to communicate information about research to the African American community. The groups were led by an experienced investigator using a standard focus group script. African American women without a diagnosis of breast cancer seen at the Breast Clinic of a large county hospital participated. Discussions were video and audio taped and transcribed. Eight focus groups were conducted (N = 45), initial content analysis (Morgan 1988) of transcripts revealed emerging themes concerning participation in research: 1) importance of informed consent; 2) lack of understanding regarding the placebo concept which was viewed as "unfair" treatment; 3) distrust of the research process due to feelings of being experimented on, and being used as a guinea pig; 4) view of medical research as being important, as well as, a way to help others, to increase knowledge, and advance science if used properly; 5) view of financial compensation as important, providing funds to assist with transportation costs, and costs of child/elder care, rather than an incentive, as well as, a means of

demonstrating consideration for participant's time and effort thereby promoting development of a "trusting relationship"; and 6) perception that research is for people who have the disease, not for healthy people, with participation possibly leading to development of the disease. Although preliminary and involving a small group of respondents these results suggest important aspects of the African American view of medical research and provide direction for developing individualized and culturally relevant strategies to potentially enhanced recruitment of African American women to breast cancer to potentially enhance recruitment of African American women to breast cancer prevention trials.

## INTRODUCTION

Despite the recent advances in prevention, diagnosis, and treatment of cancer, unfavorable breast cancer rates have persisted in African American women and, are in fact, increasing (Bal, 1992). It has been suggested that the greatest potential for improving breast cancer outcome for African American women may be realized through aggressive implementation of prevention, diagnostic, and state of the art treatment programs and participation in cancer prevention trials (Millon-Underwood, 1993).

In 1990, the Office of Research on Women's Health was established with a mandate to strengthen and enhance prevention, diagnosis and treatment of illness in women and to enhance research related to diseases and conditions that affect women. Among the areas targeted for high priority research was cancer prevention, particularly breast cancer prevention, with a goal of including African American, Hispanic and poor women in research trials (Barry, Gooding, Harris, Hazzard & Winogard, 1993; Grisso and Watkins, 1992). It is well recognized that recruitment of adequate sample sizes of eligible subjects is critical to the success of any clinical trial (Bennett, 1993). Currently, there is a lack of participation by African American women in breast cancer research trials, particularly breast cancer prevention trials. Representation of African American women in these studies is important so that questions regarding breast cancer incidence and potential measures for breast cancer prevention can be addressed, and the safety and efficacy of new prevention measures for breast cancer can be evaluated. Strategies for recruitment of special populations must be based on an understanding of the factors that influence cancer incidence and mortality in the target population (Clark-Tasker, 1993).



The purpose of this study was to identify African American women's perceptions, attitudes and beliefs about breast cancer prevention, and willingness and intention to participate in breast cancer prevention research. Research questions addressed in this study include: 1) what are African American women's views about breast cancer and breast cancer prevention; 2) what are the perceptions, attitudes and beliefs of African American women regarding medical research; 3) what factors influence African American's women's decisions to participate in breast cancer prevention research; 4) what strategies do African American women recommend to increase research participation in the African American community?

## **BACKGROUND**

Nationally funded research trials aimed at breast cancer prevention are currently underway. The NSABP Breast Cancer Prevention Trial is evaluating the effect of tamoxifen as breast cancer prevention in women at high risk; and the Women's Health Initiative is assessing as one component, the effect of dietary modification (low fat, high fruit, vegetable, and grain diet) on breast cancer prevention.

Recruitment of minority women to these trials has been difficult even when prospectively defined minority recruitment plans were required to be submitted with applications for funding. Without adequate representation, the manner in which preventive interventions will vary in their outcome across diverse populations will not be known, thus limiting the generalizability of study findings (Hansen, Collins, Malotte, et al, 1985).

Multiple factors are assumed to contribute to the lack of African American representation in clinical trials. One of the most important barriers is the Tuskegee Syphilis Experiment which is a key factor in creating an atmosphere of distrust and suspicion, that

hampers cancer research efforts in many African American communities (Mc Cabe 1994). In an extensive review of the literature, Swanson and Ward (1995) identified multiple barriers to minority recruitment. These included sociocultural barriers, economic barriers, and individual barriers. Sociocultural barriers were identified as racial and ethnic discrimination and cultural beliefs concerning health seeking behavior. Many minority populations are fearful and distrustful of the medical care system as a result of health care professional's indifference and disrespect and feel devalued by the health care system. In addition, racial discrimination and segregation produce fear and mistrust of federally sponsored programs and clinical research.

The main economic barrier to participation by minority populations was lack of access to health care in general, with lack of health insurance particularly limiting access to health care and consequently clinical trials for low-income minority populations. Individual barriers were identified as perceptions and beliefs about health and disease and fatalistic attitudes specifically regarding cancer.

There are few studies which describe the attitudes of the general public toward medical research. Many published reports are either commentaries or descriptive presentations focusing on the roles of physicians, clinics and hospitals in recruitment. Description of participants rarely extends beyond demographic characteristics and exclusion criteria for subjects enrolled in the study (Swanson and Ward, 1995).

Millon-Underwood and colleagues (1993) reported findings from a descriptive survey of 220 African American men and women in the Midwest. Results indicated that the main factors influencing research participation were the perceived efficacy of the investigational program and misconceptions regarding opportunities for research participation limited only to

those with the disease. Lillington, Weintraub & Chlebowski (1994) reported results of a process evaluation examining African American women's reasons for refusal to participate in the Breast Cancer Prevention Trial. Results revealed a lack of belief in the susceptibility to breast cancer, concern about the impact of the study medication on current medical condition and therapy, unwillingness of women with breast cancer to share their diagnosis with family members, and concerns about side effects. Moody, Gregory, Baconegra, et al. (1995) recently reported African American women's reasons for refusal to participate in clinical trials: family pressure, child care responsibility, family duties, fear of the unknown, and decreased perception of vulnerability to disease with perceived good health.

The limitations of available reports, as well as, the paucity of research specifically addressing factors influencing African American women's decisions to participate in breast cancer prevention trials support the need for further research in this area. Understanding the factors influencing decisions to participate in medical research will be useful for developing targeted strategies to promote cancer prevention research participation among African American women.

## **METHODS**

### **Setting and Sample**

The potential population of subjects for this study was comprised of African American women who attended the Outpatient Breast Clinic at a large university affiliated County Hospital in Southern California. African American women represent over 1/3 of the women receiving care at the Breast Clinic. These women are generally economically disadvantaged, and do not have medical insurance. The majority do not have breast cancer and are seen for

breast health maintenance. Eligibility criteria included: age greater than or equal to 35 years, African American ethnic background, and no personal history of breast cancer.

After review of the Breast Clinic list of registered patients over the past three years, 800 potential subjects were identified. Letters of invitation were sent to 200 randomly selected African American women identified from the listing. The letter of invitation explained the purpose of the study, study requirements, i.e., the group discussion and topic area, \$20 honorarium, and instructions for contacting the investigator's office if interested in participating in the study. Potential participants were also invited to bring a friend who also met eligibility criteria. Eligibility was verified by telephone and participants were scheduled to attend a focus group session.

Of the 200 mailed invitations, 27 were not delivered due to an incorrect address. A total of 57 women expressed interest (30.6% response rate, 57/173). Forty-five women attended the focus group sessions, including seven participants resulting from the "Bring a Friend" invitation. A total of 19 women were ineligible due to a diagnosis of breast cancer (17%), work schedule (25%), dependent care (16%), transportation problems (17%) and inability to contact after initial interest expressed (25%). Focus groups were scheduled on the same day as Breast Clinic to accommodate participant's schedules. Participants in the focus groups received an honorarium of \$20 as compensation for their time. Refreshments were also available during the group discussions.

### **Procedures**

Data was collected using a focus group format. Focus groups were structured to stimulate in depth discussion from the participant's perspective concerning perceptions,

beliefs, and attitudes about breast cancer and participation in medical research. The conceptual framework guiding the study was based on the Health Belief Model and Theory of Reasoned Action organized according to the PRECEDE Health Education Planning Framework particularly exploring predisposing, enabling, and reinforcing factors potentially influencing research participation behavior (Glanz, Lewis, Rimer (Eds.) 1990; Green, Krueter, Deeds, Partridge, 1980) (Figure 1). Discussions explored beliefs and attitudes about breast health, breast cancer, breast cancer prevention, medical research and ways to communicate information about research to the African American community.

Prior to initiation the study was reviewed and approved by the Institutional Review Board for Protection of Human Subjects. After consent, subjects participated in the focus group discussion and completed a brief self-report questionnaire regarding demographic characteristics. Eight focus groups consisting of 3 to 7 persons each were held between June, 1994 and October, 1994. The focus groups were facilitated by the investigator, experienced in focus group techniques, and an African American research nurse familiar with breast cancer issues in the African American community. All group discussions were audio taped and video taped to aid in data analysis and lasted 1 1/2 to 2 hours.

Sessions began with an explanation of the informed consent, purpose of audio and video taping, and goals for the group. Divergence of opinion was encouraged and all participants were asked to offer their opinion as it was explained that there were no right or wrong answers. The facilitators adopted a stance of curiosity and incomplete understanding and used a focus group script involving a number of open ended questions. The script consisted of core questions with subsequent probes. Script questions were reviewed by a

judge panel of three experts and tested in a pilot focus group involving support staff from the Breast Clinic, many of whom were representative of the African American participants, to determine feasibility of the approach and appropriateness of the script. Questions posed to participants included: 1) What do you do to try and stay healthy? 2) What comes to your mind when you think about breast cancer? 3) What comes to your mind when you think about preventing breast cancer? 4) What do people think about medical research? 5) When you think about participating in research about preventing breast cancer what thoughts come to your mind? 6) If we wanted to increase people's interest in participating in research what would we need to do in your community?

### **Data Analysis**

A content analysis of the group discussions was undertaken using procedures outlined by Morgan (1988) and Krueger (1988). The audio tapes of the discussions were transcribed verbatim, reviewed for accuracy and completeness, and corrected prior to content analysis. The typed transcript was marked, cut apart, and sorted according to relevance to specific discussion questions. Responses were coded independently by the investigator and African American research nurse. The organized comments of the participants were assessed and grouped according to themes expressed in the comments themselves. Comments that were mentioned by more than one individual were identified and it was noted when individuals shared a common opinion, belief or practice. Independent reports were compared, consensus was reached and summary statements were prepared. Additionally, 19 of the original 45 focus group participants returned to a group discussion to verify and validate findings by reviewing a summary of the results.

## **RESULTS**

### **Sample Characteristics**

Forty-five African American women participated in the focus group discussions. The demographic characteristics of focus group participants are shown in Table 1. The average age of the women was 51 years (range 35-91 years). Over half of the women completed a high school education with many of the women going on to complete some college or specialized training after high school (44.5%). Most of the women were either retired (22.2%) or not employed (31.1%). The majority of women (60%) reported an income level  $\leq$  \$10,000, and many (48.8%) had Medicare or Medical insurance coverage. Only a few women (6.7%) reported prior research participation and less than 20% of participants reported a family history of breast cancer.

In general participants had a great need to share personal experiences related to their own breast health (mammography, having a breast lump or having a biopsy), and experiences of family members and friends who have had breast cancer. The major findings from the discussions were categorized so as to specifically identify Predisposing, Reinforcing and Enabling Factors potentially influencing African American women's decisions to participate in medical research.

### **Beliefs about Breast Cancer**

When asked to share thoughts about breast cancer, most women reported that breast cancer caused fear, particularly fear of death, fear of losing a breast and the impact this might have on one's partner, fear of radiation and treatment side effects, and fear of pain. Most women associated breast cancer with a fatal outcome, and shared their personal experiences

with friends or relatives who had breast cancer and had died. A few participants did recognize the importance of early detection as a means of reversing the perceived fatal outcome due to breast cancer.

"...I know we always associate it (breast cancer) with death but that isn't the case all the time."

"...if you can catch it in time, it's preventable...a lot of ladies don't think this way..."

Perceived lack of susceptibility and denial were commonly expressed. Some women did not feel they were at risk for developing breast cancer and many felt that it was outside of their control, i.e. "... it's in God's hands." Many participants also felt that women would not want to know if they had breast cancer because they would feel doomed.

"...Woman are in denial... they think it's not going to happen to me...they do not get medical care when they have breast problems...they don't want to know."

### **Perceptions About Breast Cancer Prevention**

Discussion concerning breast cancer prevention was initially limited since women felt that in order to prevent breast cancer, a cause must be known. Thoughts about causes of breast cancer included chemical preservatives in food, pesticides, heredity, virus, and breast feeding. Although food was identified as a potential cause, the concept that diet, particularly a low fat diet, might prevent development of breast cancer was not addressed.

Knowledge of risk factors was limited to family history. Some women felt, however, that because they had other health problems, breast cancer would not "get them."

"...I just don't think it's gonna hit me...I just don't accept it's gonna hit me."



Others reported that it was not always easy to find out about one's family history since the older generation doesn't talk about cancer.

"...what gets me is the denial because if they [older generation] won't talk about it and tell the next generation...you don't know anything."

Most women identified screening measures such as mammograms, self-exam and regular check-ups, as well as, knowing one's family history, and prayer as ways to prevent breast cancer suggesting a lack of understanding regarding primary and secondary prevention concepts.

### **Thoughts about Medical Research**

In general, most participants felt the general public was not aware of research, "People don't think about research...they don't know about it." Common positive perceptions about research included a sense of altruism: increase knowledge, save lives, help others, as well as, a way to help oneself.

"...We found out a lot on account of doing research to better treat diseases..."

"...I think it's good, if it helps people..."

A general fear of research was also reported due to a lack of understanding about the research process and procedures that are involved, and the thought of being used as a "guinea pig," often referring to the Tuskegee study.

"...If I knew more about it, I wouldn't feel afraid of it [research]...ignorance makes you afraid..."

"...it makes me sad that they experiment with people...like being a guinea pig...they always do that with older people."

"...it [fear] all comes from the research in the South, on the Black men, the Mississippi thing (Tuskegee study)..."

Concerns about side effects and problems that may occur in the future were also expressed, as was fear of "getting the disease" by participating in the research.

### **Perceptions about the Prevention Research**

Responses varied in regard to the preferred type of prevention research i.e., diet versus pill. Some women stated they would prefer taking a pill because it was perceived to be "easier" and others stated they would prefer diet because of the "natural" approach.

"I don't want to do the research where you want me to take something [pill]..."  
Others reported that they would prefer research in which something (blood, tissue) was taken from them as opposed to taking a medication.

"I feel better if you were taking something from me than to put something in my body."

### **Sources of Distrust in Medical Research**

The issues of distrust and suspicion in medical research were raised by many participants specifically related to: government sponsored research (Tuskegee study, government control of medical care), use of placebos which was felt to be "denying people treatment", and skepticism about procedures to be done, and whether subjects would be told the truth.

"Research is fine if people know what's going on...if they [government] do it behind their back and they don't know it's going on...and something happens...that's wrong."

"Research is political...people [are] just getting rich off cancer research..."

"...if you find out you didn't get the medicine [placebo] you feel used..."

"How do we know research is being used properly..how do we know we're being told the truth..."

Building trust and gaining confidence were considered important determinants for research participation.

"...build the trust between the people and the researcher..., get their confidence so that they will know they [are] not going to be hurt."

"Give us the truth but give it in a way that we can receive it and understand it."

Many women also emphasized the importance of follow through and informing participants of the results of the research as a means of building trust and confidence

### **Importance of Informed Consent**

There was a general consensus that informed consent was the key determinant for research participation. This was operationalized as knowing exactly what procedures would be done, where and how they would be done, the risks and benefits, side effects and sharing of results.

"Research is OK, just as long as you know what you're getting into."

"I want to know before hand so I can decide if I want to get into it or not."

"...just make sure that whatever you tell them is exactly what you're gonna really be doing...in the older [ $\geq 50$  years] age group, there is nothing worse than misleading."

### **Who Participates in Research?**

A variety of opinions were voiced regarding who should participate in research. A few women felt it was everyone's responsibility.

"All people should participate...it's our responsibility..."

One participant felt that people would be more open to participating in research concerning health problems that are in the African American culture:

"...people would be more apt to participate in something if they know what it is...a certain disease that's been in their community, it's what affects that culture."

In contrast, a few women raised the question "why study me..why am I so different" suggesting they did not want to be singled out.

Some women felt people with a disease or illness who had nothing else left to try or people at high risk for developing the disease should participate in research. Participation in research by healthy people was not generally recognized since "...people are here and now...they are not worrying about the future."

### **Barriers to Research Participation**

Discussion regarding barriers to research participation often led to sharing of experiences related to receiving health care in a "county" system. Many women expressed a lack of confidence in the county health care system related to long wait times, impersonal treatment, and lack of follow-up:

"...when I come to the county hospital, I don't have any trust ...with private doctors I have trust.. you can sit and talk confidential, there's respect."

A few women shared "good" experiences in receiving health care in the county system and reported that "...if you know how the system works you can get the same treatment as a person with medical insurance."

Other barriers to research participation included time, lack of awareness, lack of interest, cost, responsibilities at home, fear, distrust and suspicion.

## **Recommended Recruitment Strategies**

Women identified compensation as an important recruitment strategy either in cash, a "free" health exam or a free mammogram.

"..it's important as a consideration for what the person is doing, the gas, the time, bus fare is sky high..."

"...[people] don't have money to come out."

"...the person is taking their time, effort, energy...it's a nice thank you."

"..if some [research programs] have a free mammogram or a free check-up...that makes a lot of difference..."

Most women felt a personal approach, using a personalized letter inviting individuals to participate in a "study" or "program" was most effective. They cautioned about using the word "research" since it generates a fear response. Participants also recommended that talking with people in the program, would be helpful.

"...give them an example of somebody that [has] been through it..."

Many women also felt that the program needed to be offered in the community, run by people with whom they feel comfortable:

"you can't just send anybody, it would have to be someone they could be comfortable with...someone to talk to them in a way they [can] understand."

Recommendations for increasing awareness included posting flyers and pamphlets in "places where they're really tuned in...most black people, especially for women, they go to church." The media (TV, newspapers, radio) was also identified as an important source of providing information to the community as was word of mouth. The importance of going to the local community was emphasized:

"Go to the community because every household is different...some don't read, don't watch TV..."

## **DISCUSSION**

The results of the content analysis suggest that African American women have some unique views about prevention and participation in medical research which have implications for developing tailored recruitment strategies. A model for recruitment, derived from focus group findings, identifies specific Predisposing, Enabling, and Reinforcing Factors which need to be considered in planning recruitment strategies for breast cancer prevention trials in the African American community. These have been summarized in Tables 2-4.

### **Predisposing Factors**

Specific Predisposing Factors are summarized in Table 2. These include knowledge deficits regarding: ongoing breast cancer studies, the concept of prevention, breast cancer risk factors, and the research process including common terminology. Although research was generally felt to be important and necessary, it was not a topic that was commonly discussed.

Providing information regarding the impact of breast cancer was felt to be important to increase understanding of the magnitude of the problem within the African American community. The women in this study tended to perceive breast cancer as a serious illness, causing a great deal of fear. Denial and an underestimation of personal vulnerability were also identified as important potential barriers to seeking health care, as well as, research participation. Knowledge deficits, denial and perceived lack of susceptibility have been previously recognized as barriers to research participation. (Mack, McGrath, Pendleton, Zieber, 1993).

A fatalistic attitude towards breast cancer outcome was also apparent, as has been previously identified in the African American population (Bloom, Hayes, Saunders, & Flatt, 1987; Underwood, 1992). It is interesting that factors associated with fatalistic beliefs about cancer outcome, i.e., lack of cancer knowledge, limited access to health care, fear of being used as a "guinea pig," have also been identified as important determinants of research participation (Dula 1994; Guillory, 1987). Powe (1995) recently speculated that the development of fatalistic perceptions towards cancer may be related to an individual's actual experiences with cancer among their family members and friends. This was apparent from the focus group discussions. Many African Americans have witnessed the repeated cycle of late cancer diagnosis and death and, therefore, may have more fatalistic beliefs. They may be less apt to participate in preventive health behaviors or be motivated to participate in prevention related research because it is perceived to not matter.

Ethical issues related to research participation emphasized the importance of informed consent. Participants felt it was necessary to know exactly what would be required in the research, particularly, what would be done, how long it would take, the side effects, risks and benefits. This information was considered necessary in order to be able to make a decision about study participation. Research was thought to be important and necessary for increasing knowledge and advancing science, "if used properly", suggesting participants were not certain about whether it was right or wrong. Research on animals was perceived to be acceptable but research using humans was less certain. This finding may be the result of the extensive knowledge of the Tuskegee Syphilis Experiment which has generated wide spread suspicion and distrust among the African American community regarding medical research (Freeman,

1993).

The research process was also not well understood. Randomization and use of a placebo were viewed as "unfair" and "denying people treatment." These concepts need to be explained using concrete examples and simplistic language in order for individuals to understand the rationale for these procedures in applicable studies.

Another interesting finding was the perception that research was for people who had the disease or people at high risk rather than for healthy people. This has been previously reported by Millon-Underwood, et al, (1993) and has definite implications for prevention trial research participation. A possible explanation has been that health care is generally important only in the presence of symptoms, with prevention measures receiving low priority (Bloomenthal, 1995). Although participants in the focus group discussions were well aware of healthy behaviors, many did not practice these behaviors. It was interesting that the knowledge of healthy lifestyle behaviors did not seem to translate into the concept of prevention. In fact, in the initial focus group, the first focus group question asked, "What do you do to try and prevent disease?" Responses were limited, the concept of prevention was not well understood. Subsequently, participants were asked, "What do you do to try and stay healthy?" which generated more fruitful discussion.

### **Reinforcing Factors**

Findings from this study identified positive, as well as, negative reinforcing factors potentially influencing research participation (Table 3). Important referents were identified as family members and physicians, as well as, persons who are participating in the program. Gaining local community endorsement, and physician support were considered important for



enhancing acceptance of research participation.

The influence of religious beliefs on health and illness was strong. Religious beliefs may operate as a mechanism influencing a perceived external locus of control over health, i.e., health is in God's hands, with prayer being identified as a mediating mechanism to influence health or disease outcomes. This may impact acceptance of preventive health behavior and participation in prevention research negatively if individuals do not perceive control over their own health (Jackson, 1991).

The fact that research may be sponsored by federal government agencies was not necessarily perceived in a positive light. The climate of racial discrimination and segregation in our society has resulted in fear and mistrust of federally sponsored projects, clinical research and academic medicine (Nickens, 1990; Thomas, Pinto, Roach, and Vaughn, 1994).

### **Enabling Factors**

Enabling factors which may potentially facilitate or inhibit research participation behavior are summarized in Table 4. Access to ongoing research was limited due to lack of awareness of ongoing breast cancer prevention trials, i.e., the NSABP Breast Cancer Prevention Trial and the Women's Health Initiative, as well as, limited availability of programs in the local community. Participants were also unsure about where they could go to get information regarding research programs. This suggests that there has been little publicity regarding these trials in the African American community.

Reimbursement for research participation was viewed as an important facilitating factor. Participants did not necessarily view cash payment or even "free" health evaluations as incentives, rather they viewed these activities as means for enabling participants to complete

required study activities which may otherwise be unaffordable due to costs for procedures, lack of transportation, lost wages and costs for child care. Unique to this study was the finding that reimbursement was viewed as recognition for participant's time, effort, and energy resulting in a feeling of being valued for participating in the program. Reimbursement was felt to be a means for building trust and confidence, and hence a way to possibly reduce the current widespread suspicion and mistrust felt in the African American community related to research participation. Incentives such as transportation, child care, and cash payments have been used in research studies involving minority populations in the past (Moody et al. 1995; McCabe et al. 1994; Murdaugh 1990). The sole impact of the use of reimbursement as a recruitment strategy in minority populations, however, has not been reported.

Participants also emphasized the importance of following through and notifying subjects about the results. As was demonstrated in this study, 47% of the participants returned to the validation discussion session almost two years after the study began because they were interested in the outcome.

The use of a personalized approach was also recommended, e.g., personalized letters of invitation and individual doctor recommendations. This combined with follow through and reimbursement may lead to building trust and confidence resulting in increased African American participation in breast cancer prevention research.

Barriers identified were similar to those reported in the literature including concerns about side effects, fear of the unknown, poor quality of care (impersonal approach, long waits), distrust, transportation problems, costs, and time (Swanson and Ward, 1995).

In summary, based on these findings, recruitment strategies targeting African American

women for breast cancer prevention research participation need to include activities and approaches to increase awareness, alter misconceptions, reduce barriers and maximize facilitating factors.

### **Limitations**

Findings from this study are considered preliminary and are not generalizable beyond the African American women who participated in the focus group discussions. Because focus groups involve small numbers of individuals, sampling techniques are often not scientific and open to selection bias. It will be important to extend the research using quantitative approaches, conducting studies which include women who are more representative of the African American population in terms of education, income and age range appropriate for the target research.

### **CONCLUSION**

Findings from the focus group discussions provide insight into the perceptions, attitudes and beliefs of African American Women regarding breast cancer, breast cancer prevention, research participation and strategies to enhance recruitment of African American women to breast cancer prevention research trials. Although research was generally thought to be important and effective, skepticism and suspicion were expressed when individual participation was discussed. Important factors promoting research participation by African American women centered on establishing credibility at the local level (community leader, organization, and physician endorsement), developing trust and building confidence (ethnic matched personnel, talking with people in the program, personalized recruitment approaches); assuring informed consent; increasing access and availability (take the program to the

community, publicize the program); overcoming barriers (cost, transportation, time, offering dependent care); developing communication messages using an altruistic appeal; offering "free" mammograms and health evaluations; and providing financial compensation for individual time and effort required to complete study activities (Figure 2).

While these are preliminary findings in need of further exploration in larger groups of African American women, they do provide direction for the development of culturally relevant strategies to enhance recruitment of African American women to breast cancer prevention trials. Nurses increasingly are in positions to participate in planning, developing and implementing recruitment strategies to achieve successful accrual of eligible participants to ongoing clinical trials. Incorporation of techniques and approaches tailored to the needs of special populations may generate increased recruitment yields and permit generalizability of study findings to women of all ethnic backgrounds and socioeconomic strata.

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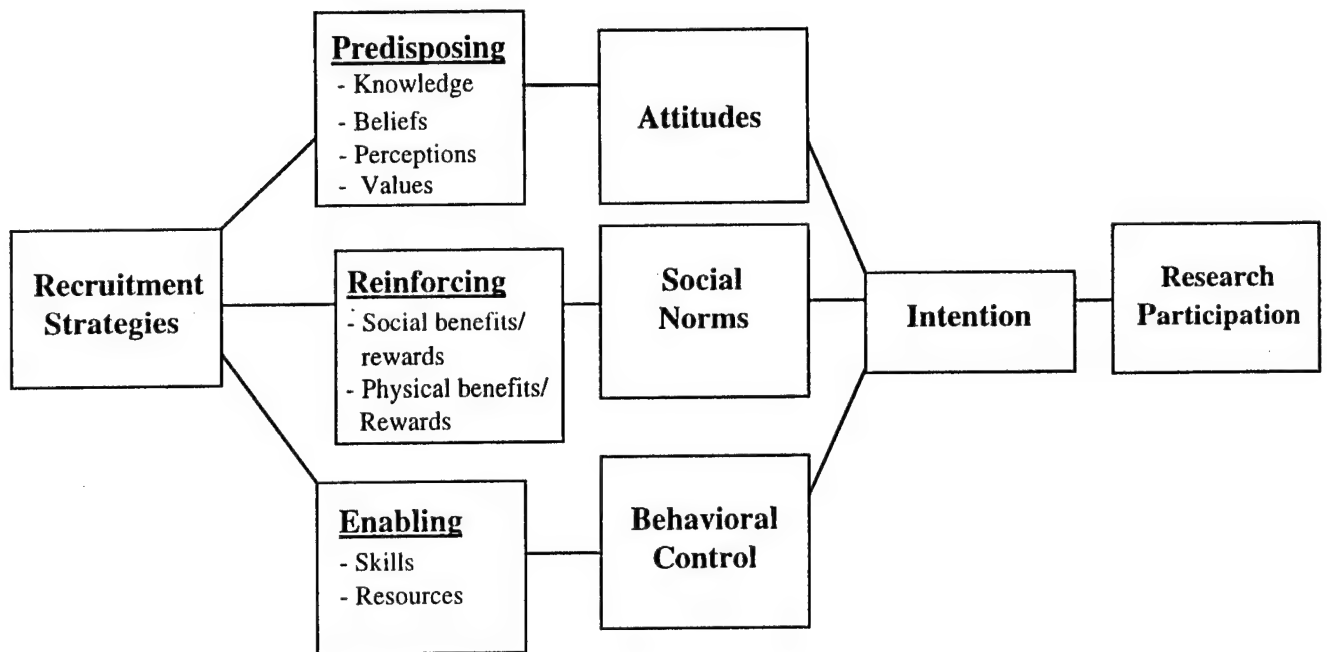
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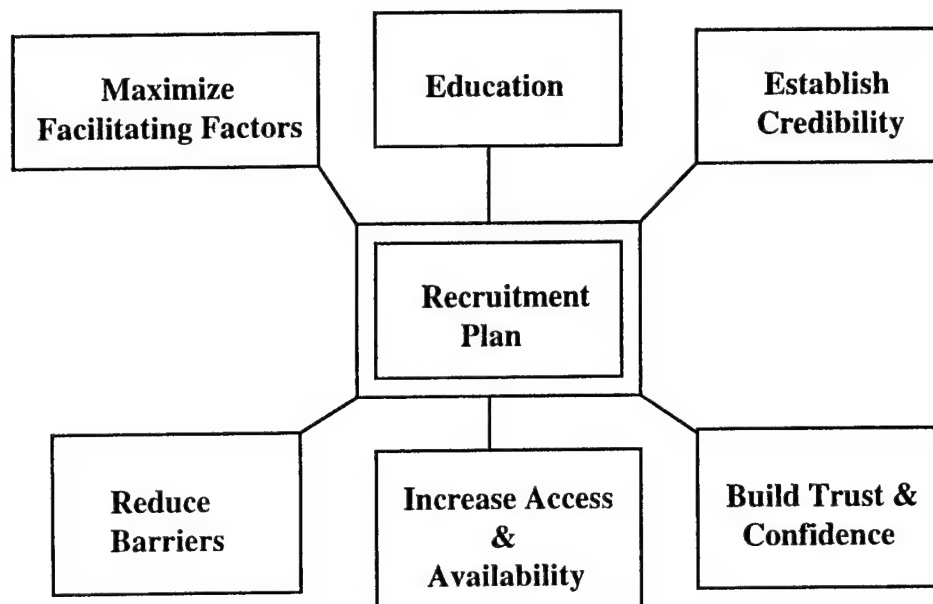
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Figure 1. Conceptual Framework Based on Health Belief Model and Theory of Reasoned Action.





**Figure 2. African American Prevention Research Recruitment Plan: A Six Pronged Approach.**



**Table 1 - Demographic Characteristics of Focus Group Participants**

N = 45

Education	<u>No</u>	<u>%</u>
Less than High School	9	20.0
High School	16	35.5
College	20	44.5
Mean Age (years)	51 (range 35 - 91)	
Martial Status		
Single/Never Married	9	20.0
Married/Living together	10	22.2
Separated/Divorced	19	42.2
Widowed	7	15.6
Employment		
Full Time	8	17.8
Part Time	8	17.8
Not Employed	14	31.1
Retired	10	22.2
Other	5	11.1
Income		
≤ \$10,000	27	60.0
> \$10,000 ≤ \$20,000	12	26.6
> \$20,000	6	13.3
Health Insurance		
Medicare/Medical	22	48.4
Private Insurance	8	17.8
No insurance	15	33.4
Family History of Breast Cancer		
Yes	8	17.8
No	37	82.2
Prior Research Participation		
Yes	3	6.7
No	42	93.3

**Table 2. Predisposing Factors**

Knowledge Deficits:

- Ongoing Research
- Breast Cancer Risk Factors
- Breast Cancer Incidence
- Concept of Prevention
- Research Process/Terminology

Attitudes and Beliefs:

- Fear
- Breast Cancer Susceptibility
- Denial
- Fatalism

Ethics of Research

- Right vs Wrong
- Informed Consent:
  - Procedures
  - Risks/Benefits
  - Side Effects
- Randomization/Placebo
- Racism
- Who Participates

### **Table 3 Reinforcing Factors**

- Referents
  - Family
  - Physician
  - People in Program
- Community Leader, Organization Endorsement
- Religiousness
  - External Locus of Control
- Government Sponsored Research
- Social Desirability

#### **Table 4 Enabling Factors**

##### **Facilitating Factors:**

- Availability of Research
- Access to Research
- Compensation
- Trust/Confidence:
  - Personalized Approaches
  - Follow Through
- Benefits

##### **Barriers:**

- Side Effects
- Risks
- Time
- Cost:
  - Transportation
  - Lost Wages
  - No Insurance
  - Dependent Care
- Perceived Poor Quality of Care
- Fear of Unknown
- Distrust